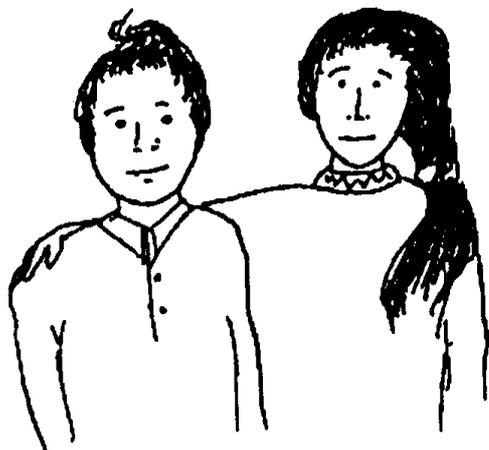


# Fact sheet 1: News breaking and survival strategies



Finding out that your child has special needs is likely to be very painful. For many parents, this isn't exactly the child you expected or hoped for. You probably feel unprepared and fearful of what might happen in the future.

If this is how life is for you right now, it may be worth thinking about what you can do to make better sense of what you are finding out, and make life more manageable.

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**If you are expecting news, take someone with you for support.** Distressing news is hard to hear and it's just not possible to take in all you are told, ask questions and keep an eye on your child at the same time.

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**If English is not your first language, ask for an interpreter.** A good interpreter will help everyone understand each other's concerns more easily. Ask that letters, reports and assessments are translated into your language.

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**Don't worry unnecessarily;** make a list of questions you want to ask and take this with you. Ask about the things you are most afraid of, sometimes a consultant can give accurate information or advice that may reassure you.

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**Ask if you don't understand what has been said.** If you are still confused, ask again until whatever is unclear has been explained so it makes sense.

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**Ask what will happen next.** What is the plan? Who can you speak to regularly for advice? Where can you get written information about your child's condition, about services, benefits and getting practical help?

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**Don't be rushed, take time to think.** If you have to make a difficult decision, say about treatment or surgery, and you don't feel confident that you have explored every avenue on your child's behalf, ask for another opinion.

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**Professionals can't always tell you how things will turn out.** Accept that they try to respond to your worries as honestly as they can, even when they can't make a firm diagnosis, or predict how things might turn out for your child in the future; sometimes they just don't know.

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**Professionals should do their best to share news sensitively** and use an approach and language that's respectful to you and values your child. If you are unhappy about the way you are treated, write and complain. If you just sit with your hurt or anger and say nothing, the way they work won't change.

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**Sharing news with other significant people in your child's life**, like siblings, grandparents and friends can be really tough, so ask for help.

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**In the early days or during a crisis, appoint someone outside your immediate family**, like mum, or best friend to be the contact person to field calls; let someone else pass on messages.

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**Talk about how you are feeling** with the rest of the family but avoid blaming each other. Families who talk, support each other better.

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**Don't be afraid to say if you are struggling**. Unless you look like you are falling apart, most people will imagine you are coping well. Gather people around you who listen and really try to understand.

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**Try to keep a balance in your life**. Put yourself first sometimes; if you go under everyone will suffer. Not every minute of your child's life needs to be crammed with therapies and useful stuff; everyone needs to relax and enjoy fun times as well, so make time to do things as a family.

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**Practice asking for help**, so that when other people offer, you know what you need most and can tell them, before you hear yourself saying, 'it's OK, I can manage' or accepting 'help' that in reality, makes your life more difficult. Think about counselling, it's time just for you. Call Amaze for details of free or low cost counselling services locally.

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**Be prepared to deal with well-meaning but insensitive comments sometimes**, even from family and close friends. In time you'll find you get better at hearing what people mean to say.

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**Joining a parent support group can be a life-saver**; other parents are a great source of information and meeting parents with older children with the same condition (who have been there before you and survived) can help you feel you will be able to manage. To find support groups, visit Amaze's website at [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk). We have a page that lists regular local groups in our 'News and events' section or you can search our 'Useful contacts' for more groups for children with specific conditions. Do make sure any groups you join are supportive. If you come home feeling worse, then it's not worth it. Nationally, Contact a Family (0808 808 3555 [www.cafamily.org.uk](http://www.cafamily.org.uk)) can put you in touch with a group if your child has a rare condition. They also have an online forum called Making Contact ([www.makingcontact.org](http://www.makingcontact.org)) which puts parents in touch with one another.

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### For more information contact:

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This fact sheet is one of a wide range produced by Amaze and available via our helpline or website. Others you may find particularly useful are: (2) Conversations, Correspondence and Consultations; (5) Admissions to Hospital; and (17) Getting the Most Out of Appointments with Health Care Professionals.

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